

# Holistic paediatric diabetes care—evaluation of a new rural model

**Peter Goss<sup>1</sup>, Megan Paterson<sup>1</sup>, Jay Renalson<sup>1</sup>**

<sup>1</sup>Gippsland Paediatrics

## Abstract

Optimal management of diabetes includes a multidisciplinary team approach. Diabetes services to children and adolescents in rural settings are variable and currently there are no described models of care that compare favourably with the larger metropolitan multidisciplinary teams.

The aim of this study was to explore the feasibility of a new holistic model of care to deliver intensive insulin therapy to rural children with Type 1 diabetes, thereby achieving standards of care which would be defined as optimal by the NHMRC of Australia.

The study was set in a rural based paediatric practice, which cares for approximately 59 children and adolescents with Type 1 diabetes across a broad regional area.

In 2007, the rural paediatric practice employed a credentialed diabetes educator and a credentialed mental health nurse (counsellor) to create the core diabetes team, with linkages and input from other regional diabetes educators, dieticians, endocrinologists and paediatricians. Five multidisciplinary diabetes clinics were conducted at regular 3 monthly intervals. In mid 2007 the team commenced a locally run insulin pump program, one of the first of its kind in regional Australia.


Patient outcomes were measured in terms of metabolic control, patient satisfaction and quality of life. After 18 months of clinic operation, metabolic control had improved significantly compared with the previous two years and was comparable to that of major paediatric metropolitan units. There was overwhelming acceptance and embracing of the model by patients and parents. Quality of Life measures demonstrated that the previously described significantly greater adverse impact of diabetes upon rural children compared to urban diabetic youth had disappeared. Team members indicated great professional satisfaction with the team approach. Logistical issues arose and were worked through.

The model was supported by a sponsored grant. To make the model cost effective in its own right, the CMBS including Enhanced Primary Care rebates should mirror the NHMRC Clinical practice Guidelines for paediatric diabetes care. Multidisciplinary visits should be expanded to 16 rebatable visits and, rural Credentialed Mental Health Nurses should be eligible for focused psychological strategies rebates for the many rural diabetic children requiring ongoing psychological assistance.

Multidisciplinary holistic child diabetes care can be successfully achieved in a rural setting with results comparable to large metropolitan units with significant improvements in quality of life and excellent patient and professional satisfaction

## Background

The NHMRC recommends that every child and adolescent with type 1 diabetes, including those from rural and remote areas, should have access to optimal medical management. (1) Optimal management of childhood diabetes includes a multidisciplinary team approach which is difficult to achieve in a rural



setting. A national needs assessment of children and adolescents with diabetes in 1999 (2) found that rural families “remain disadvantaged in terms of their ability to access all aspects of specialist diabetes care and psychological support.” Currently there are no described multidisciplinary models of care for rural children and young adults with diabetes that compare favourably with the larger metropolitan multidisciplinary teams and as such, children with diabetes in rural areas remain disadvantaged.

A comparison of rural and urban youth in Australia (3) demonstrated that although medical control and diabetes knowledge was comparable to tertiary centres, access to Credentialed Diabetes Educators (CDEs) dieticians and a multidisciplinary team care approach was less for rural children. Measures of quality of life showed a significantly greater adverse impact by diabetes in the rural group, particularly in self esteem, parent emotional impact, family cohesion and mental health.

Metropolitan tertiary centres are government funded to provide multidisciplinary diabetes teams and onsite pathology to measure glycaemic control. There is no such specific funding for rural services. There are significant logistical issues in creating multidisciplinary diabetes teams in rural and regional areas. Many smaller regional health centres have no public outpatients. The rural model has been generally based around regular private visits to a consultant paediatrician, with CDEs and other potential members of a multidisciplinary diabetes team located separately within a public health service. Hence patients must arrange multiple visits at different times to the various service providers, whilst measurement of HbA1c requires an additional visit to a pathology department. In effect the rural child may require over 14 separate visits to a diabetes health care provider to receive the same input that may be gained by only 4 visits to a metropolitan team.

The response from patients has been poor adherence to the recommended visits. Cameron et al (3) demonstrated that only 5 of 13 local rural patients accessed a diabetes educator (DE) in the preceding 12 months (35%). This has resulted in an inefficient team model, with little multidisciplinary input and with information sharing being severely compromised. Consequently, because the identified issues have not been addressed the NHMRC recommendations have not been effectively implemented in rural areas.

Outreach visits by paediatric endocrinologists working with local paediatricians have not been successful in gaining better glycaemic control in poorly controlled patients. This is because poor control is often a result of psychological or family issues, which are best addressed by a multidisciplinary team that includes psychological skills.

The provision of outreach services by metropolitan tertiary diabetes teams occurs in some areas of Australia, but there are no published data as to the effectiveness of this model. The concept may work well if worked in collaboration with local services. However, such a model risks local paediatricians and CDEs being somewhat sidelined, reducing their credibility and reducing opportunities to develop further skills with emerging technologies. Consequently, the ability to provide effective ongoing local medical and psychosocial support is compromised.

Sale is located 210km east of Melbourne and is the regional paediatric service centre for Central and East Gippsland. Regular paediatric outreach clinics are provided from Sale to Bairnsdale, a further 75km east. From the early 2000s, attempts were made in Sale and Bairnsdale to develop a multidisciplinary team approach to paediatric diabetes care in the public health system. However local health services could or would not provide additional CDE, dietician and psychology resources to allow such a team to evolve and the inflexibility of the public health system proved locally insurmountable. Attendance to a CDE remained rare, attendance to a dietician was even rarer and psychosocial assistance was negligible. In 2007, an audit of the local paediatric patients demonstrated that glycaemic control had deteriorated beyond acceptable levels in 2006 and hence a new model of care, separate from the public system was conceived and developed.

## Aim

The aim of this study was to explore the feasibility of a new holistic model of care to deliver intensive insulin therapy by a multidisciplinary health care team to rural children with Type 1 diabetes and thereby achieve standards of care which would be defined as optimal by the NHMRC of Australia.

## Methods

Eligibility for this study was defined as being less than 20 years of age with Type 1 diabetes and being a patient of "Gippsland Paediatrics", an independent, rural paediatric practice based in Sale in Eastern Victoria. The practice comprises 2 paediatricians who provide the consultant regional paediatric services locally, including to almost all children with diabetes in the region. Gippsland Paediatrics cared for 48 children and adolescents with type 1 diabetes in 2006, increasing to 59 patients in 2008.

During 2007, Gippsland Paediatrics employed a CDE and a Credentialed Mental Health Nurse (CMHN) with expertise in child, adolescent and family loss, grief and trauma counselling. We considered those psychological and counselling skills imperative to address the emotional needs of the child and family in a proactive manner. The core multidisciplinary diabetes team comprised one general paediatrician with an interest in diabetes, the CDE and the counsellor. Other regional DEs, dieticians, paediatricians and general practitioners were invited to provide clinical input, including at multidisciplinary case meetings.

Rather than being reviewed in random appointments, the children with diabetes were grouped and specific days set aside for "Diabetes Clinics". Five such multidisciplinary diabetes clinics were established—three clinics in Sale and two in Bairnsdale at regular 3 monthly intervals comprising of approximately 10 patients in each clinic. Patients were seen individually by the CDE, counsellor and paediatrician; although in Bairnsdale some group consultations initially occurred with CDE, counsellor and /or dietician. Following consultations in the morning, the core diabetes team met together along with dieticians and other local DEs in case conference for all patients later in the day to share information and devise further management strategies.

The patients who lived too remotely to attend the diabetes clinics for the full multidisciplinary approach, or retained a preference (for many reasons) for the old model of care were designated as "non-clinic" patients.

Consultations with paediatric endocrinologists and tertiary diabetes team members continued as phone or email discussion rather than direct face to face consultations.

An onsite HbA1c analyser (Bayer DCA 2000) was purchased by a local children's charity (the Kate Buntine Children's Trust) to be used in the diabetes clinics. Onsite point of testing reduces the impact of the disease on children by negating the need for an additional attendance at pathology, apart from annual complication screening tests.

In mid 2007 the team commenced a locally run insulin pump therapy (IPT) (Continuous Subcutaneous Insulin Infusion) program, one of the first of its kind in regional Australia.

In late 2008, the Kate Buntine Children's Trust also purchased two Continuous Glucose Monitoring System (Medtronic MiniLink Real Time) units to assist better management of patients with diabetes.

A random sample of 20 patient records in Sale was examined to calculate the frequency of DE visits in the 5 years between 2002 and 2006 inclusive, excluding attendances in the first year after diagnosis or inpatient attendances.

The feasibility of the model was measured in terms of effectiveness of glycaemic control, patient satisfaction and quality of life.

A 12 month average HbA1c for each individual patient and frequency of measurement of HbA1C was compared in the years 2006 (48 patients) and 2007 when clinics were in the establishment phase (53 patients). The HbA1c at the final clinic of 2008 (47 clinic patients and 12 non-clinic patients) was measured and compared with the 2006 average. Three patients referred in the last 3 months of 2008 were excluded from analysis. The student's t test was utilised to determine statistical significance of HbA1c differences.

The authors devised patient satisfaction questionnaires for completion after 12 months of diabetes clinic attendance to evaluate the response to the holistic clinic concept. The survey was completed by patients if 13 years of age or older or by parents if the child was under 13 years. Nine questions were asked relating to impact upon lifestyle, support, diabetes control and understanding, awareness of complications and dealing with the emotional aspect of diabetes. Responses were considered negative if answered "not at all" or "a little" and the response considered positive if the response was "moderately", "very" and strongly positive if rated "extremely".

The Authorised Australian Adaptation of Quality of Life Questionnaire Parent Form (PF50) was selected as the tool to measure Quality of Life in order to compare with data utilising PF50 in a group of paediatric diabetic patients from the same region in 1999 (3).

The PF50 is suitable for children under 10 year and the youth self report CHQ CH87 was developed for ages 10 and older. The PF50 was completed by parents of all ten children attending clinics less than 10 years of age after 12 months of clinic attendance. The CH87 is in process of measurement for clinic patients between 10 and 18 years and results will be reported elsewhere.

The CHQ tool has been validated on Australian children with diabetes (4). There are 3 sections—the physical, psychosocial and family domains. The subscales in the physical domain comprise physical functioning, role physical and bodily pain. The psychosocial domain includes role emotional/behavioural, behaviour, mental health and self esteem. The family domain includes patient impact (emotional), parent impact (time), family activities and family cohesion.

After 12 months, the core diabetes team met to discuss the concept, the strengths and weaknesses of the model, including the professional satisfaction gained by working in such a team.

The financial feasibility of the model was examined, with the cost of employing the staff compared with the CMBS rebates for various services. The NHMRC recommendations for optimal care of children with Type 1 diabetes were compared with available CMBS item numbers for those children.

## Results

The sex distribution, mean age and numbers attending clinic are described in Table 1. Of 59 patients in December 2008, 44 were studied as clinic patients and 3 were excluded because of very recent referral. The 12 patients with diabetes who did not attend the clinic in 2008 included 5 patients residing in more remote areas of Gippsland or Melbourne, 3 with daytime work commitments, and four who preferred to attend private consultations for reasons which included interference with Year 12 studies, poor attendance reliability (2 patients) and reluctance to address outstanding psychological issues.



**Table 1**

Year	Number	Male	Female	Mean Age	N clinic	N Non Clinic
2006	48	24	24	13.4	0	48
2007	53	25	28	13.6	36	17
2008	59	29	30	14.0	47	12

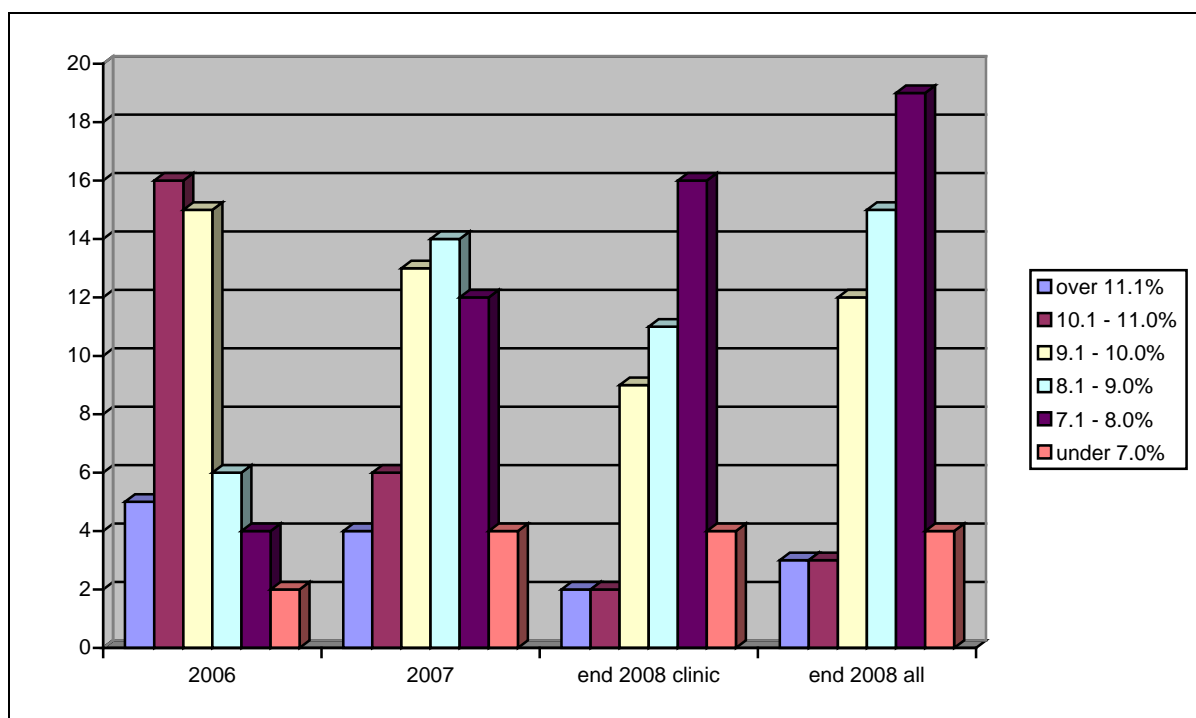
The audit of 2006 metabolic control revealed 48 patients with a mean HbA1c of  $9.6\% \pm 1.81$  (median 9.7%), significantly worse than Australian metropolitan tertiary standards in 1999 of mean HbA1c 8.6% (5). As the clinic model was being established during 2007, the median HbA1C of 53 patients fell to 8.9% (mean  $8.8\% \pm 1.40$ ,  $P=0.003$ ).

In late 2008, after 18 months of clinic operation, the 44 patients attending clinic had a median HbA1C of 8.1% (mean  $8.5\% \pm 1.3$ ). The median HbA1C of the non-clinic group was 9.0% with a mean of  $9.3\% \pm 1.72$ . The overall median HbA1c of all children with diabetes attending Gippsland Paediatrics at the completion of 2008 was 8.2% (mean  $8.6\% \pm 1.41$ ) (Table 2). The overall improvement in HbA1c from the 2006 figures was statistically significant ( $p=0.0002$ ). (Figure 1) Anecdotal reports of 2008 glycaemic control at Melbourne tertiary diabetes units suggest a mean HbA1c of between 8.2% and 8.5% (personal discussion).

**Table 2**

Year	Number	Mean HbA1c	SD	Median HbA1c	Range	N 7.5%	N 8%	HbA1c Tests /yr
2006	48	9.6	1.81	9.7	6.6-11.5	3 (6%)	5 (10%)	3.3
2007	53	8.8	1.40	8.9	5.6-11.5	8 (15%)	16 (28%)	3.0
Final 2008 Clinic	44	8.5	1.3	8.1	6.5-13.0	10 (24%)	20 (45%)	4.0
Final 2008 non Clinic	12	9.3	1.72	9.0	7.3-13.5	1 (8%)	3 (25%)	3.0
Final 2008 all	56	8.6	1.41	8.2	6.5-13.5	11(20%)	23 (41%)	3.8

**Figure 1 HbA1c values from 2006 to 2008**



**Physical domain** (physical functioning PF, role physical RP, general health GH and bodily pain BP)

**Psychosocial domain** (role emotional/behavioural REB, behaviour BE, mental health MH and self esteem SE)

**Family domain** (parent impact (emotional) PE, parent impact (time) PT, family activities FA and family cohesion FC) The NHMRC recommends a target HbA1C of less than 7.5% for older children and adolescents, with a slightly higher target for younger children. In 2006, only 3 patients (6.25%) achieved such a result compared with 10 patients (24% clinic patients) by the end of 2008.

By December 2008, 25 of the 44 clinic patients were managed with IPT (58%). The mean HbA1c after at least 3 months of IPT (22 patients) by late 2008 was 7.9% ± 0.96, median 7.7%). Four of the 14 non clinic patients (29%) were managed with IPT. The mean HbA1c after at least 3 months of therapy for those patients in late 2008 was 8.7% ± 1.01, median 9.5%). Overall, the IPT group had mean HbA1c of 8.1% ± 1.0 (median 7.8%).

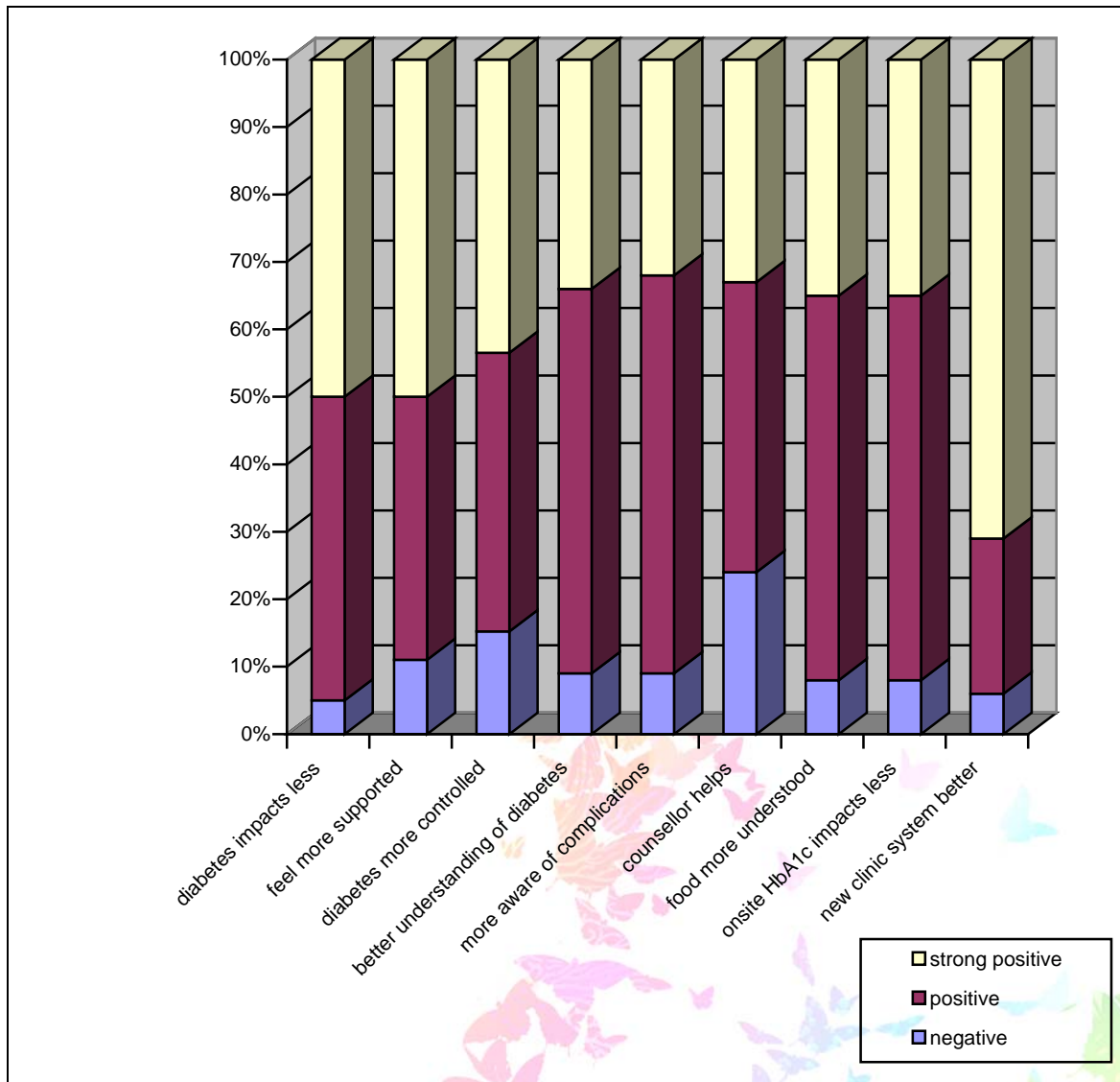
The frequency of testing for glycaemic control increased from overall 3.3 tests per year (2006) and 3.0 tests per year (2007) to 4.0 tests per year in 2008 for clinic patients while non clinic patients remained at 3.0 tests per year.

The number of contact visits with a CDE after the first year of diagnosis and excluding inpatient stays increased from median 0.6 contacts per year (mean 0.8 ± 0.61) to 4.0 contacts per year in 2008. In addition those 29 patients commencing insulin pump therapy had a further 6 to 10 CDE contacts each between August 2007 and December 2008. From September 2008 contact for those on IPT also included regular phone and email contact.

The model was overwhelmingly accepted and embraced by patients and parents with reporting of significantly less impact upon their lifestyle. (Figure 2) Thirty eight clinic patients or their parent answered the survey (86%). 95 % of respondents agreed that seeing the health team on one visit impacted less on their lifestyle, with 50% of respondents strongly agreeing. 89% felt more supported by the team approach, and 86% also felt that their diabetes was more under control with the team approach. 91% felt they had gained a better understanding of their diabetes and were more aware of diabetic complications. 76% felt

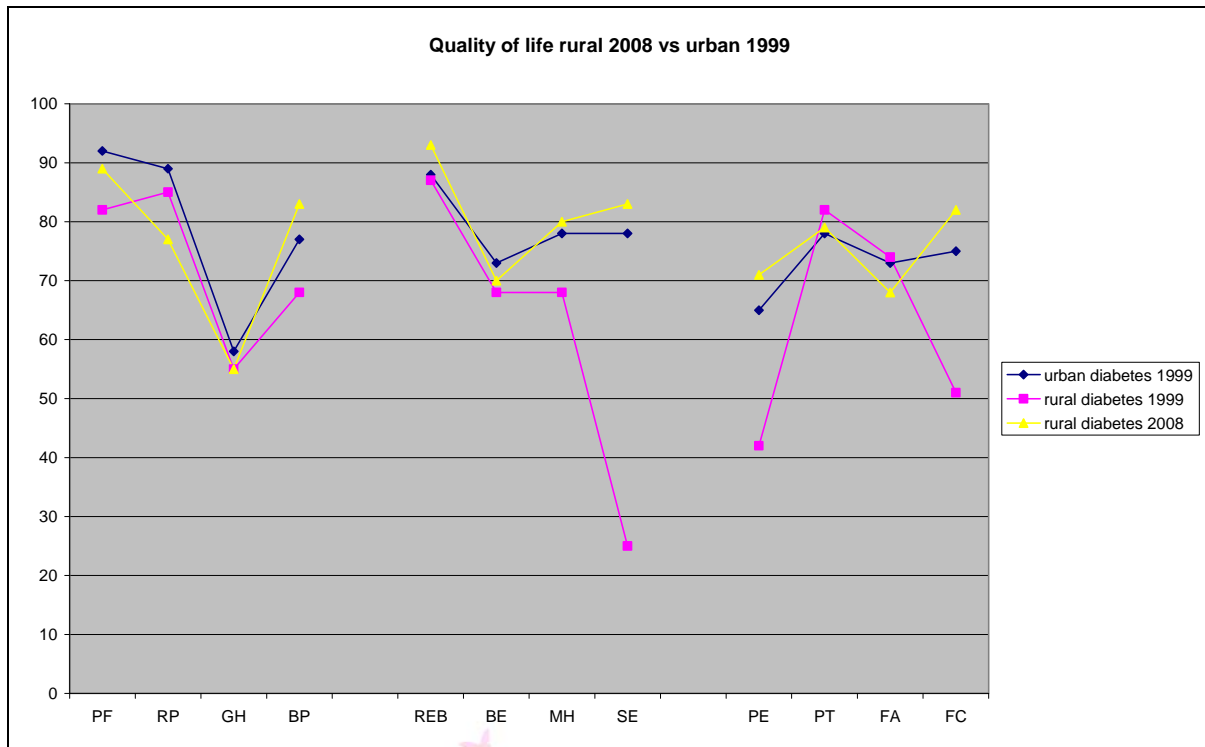
the counsellor was important in supporting the emotional aspect of diabetes and 92% felt the clinic made them more aware of food issues, even though a dietician was not present at the 3 Sale clinics. 94% felt that on site HbA1C impacted less upon their lifestyle and 94% (with 71% agreeing strongly) preferred the new clinic system.

**Figure 2 Results of Patient Satisfaction Survey December 2008**

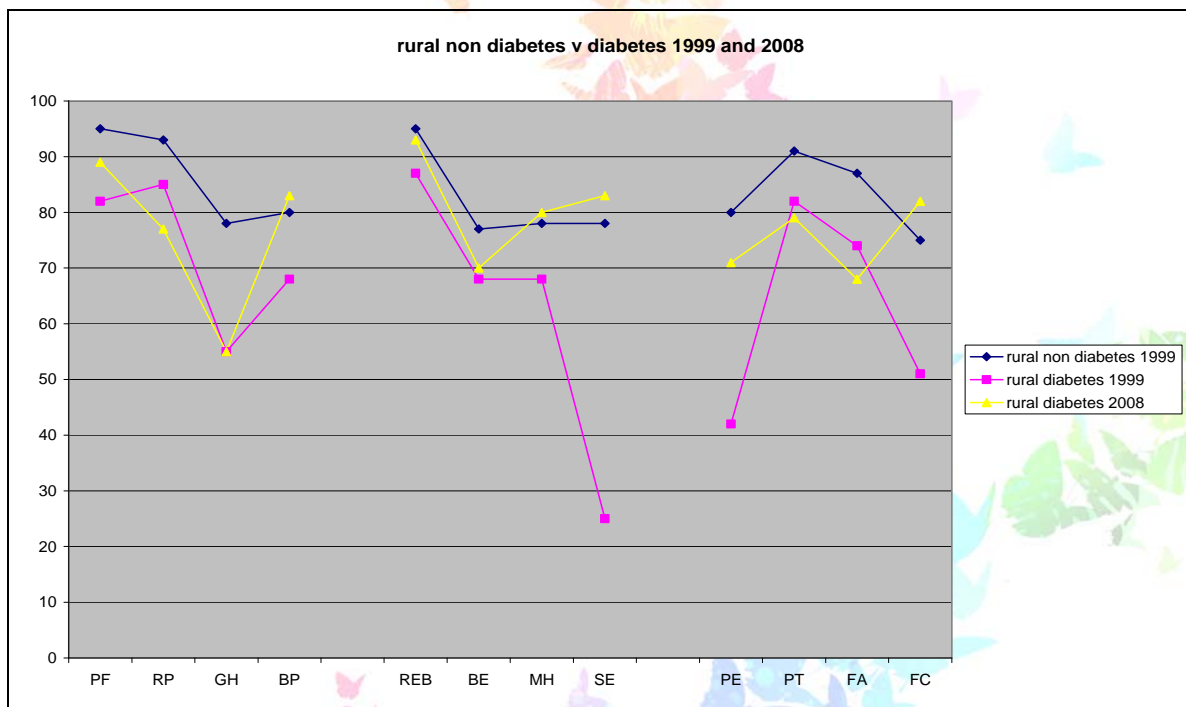


Quality of Life survey data has revealed significant improvements in previously reported adverse impact parameters for rural children with diabetes. Moderate effect size on mental health and large effect sizes for self esteem, parent impact (emotional) and family cohesion from the 1999 rural diabetic youth have disappeared. (Figure 3) Rural children with diabetes now outscore the 1999 urban diabetic youth data in 1 of 4 physical subscales, 3 of 4 psychosocial subscales and 3 of 4 family subscales. (Figure 3) They also outscore non diabetic rural youth in on 4 of the 12 subscales with marked improvement in psychosocial and family subscales. (Figure 4)

**Figure 3** Quality of Life; Comparison between urban diabetic youth 1999, rural non diabetic youth 1999 (3) and rural diabetic youth (holistic model) 2008



**Figure 4** Quality of Life: Comparison between rural non-diabetic youth 1999, rural diabetic youth 1999 (3) and rural diabetic youth (holistic model) 2008



Team members regularly discussed and refined the model and met formally to review the clinic at the completion of one year. The major issues included role delineation and how best to ensure a supportive, non confrontational approach which did not intimidate patients. The consultation behaviour and team



interaction was an important part of the success of the model. The counsellor role of being a core member of the team was extremely valuable and facilitated much easier referral when family and emotional problems arose. A myriad of social situations were encountered in the families, including the terminal illness and death of a parent, domestic violence, parental separation, alcohol and drug addiction and significant psychological disorders including severe anxiety disorder and personality disorder. It was felt to be imperative to have an efficient operational system that would keep appointments to time. Team members expressed great professional satisfaction with the team approach.

The model did not incur any additional cost to the patient, apart from an annual visit to their general practitioner for an Enhanced Primary Care (EPC) plan which currently cannot be generated by a paediatrician. Gippsland Paediatrics employed the CDE 2 days per week and counsellor for each clinic day and to follow up children with psychological issues on an as needed basis. The use of the Commonwealth Medical Benefits Schedule (CMBS) (7) multidisciplinary case conference rebates assisted reimbursement of team member costs. However the NHMRC recommendations enacted by the holistic model were inadequately supported by the CMBS. Because the HbA1C analyser was not part of a recognised pathology department, Medicare would not rebate the test (equivalent to the cost of the test) even though the analyser was identical to those in metropolitan tertiary clinics and the local pathology service. The paediatrician and CDE provided a non remunerated 24 phone contact service to all patients.

## Discussion

The impact of disease of type 1 diabetes is significant, with life expectancy reduced by 15 years on average (JDRF). Over 50% of patients with Type 1 diabetes will develop severe health complications as a result of the disease after 20 years. Maintaining optimal glycaemic control minimises risk of complications, so there is an urgency to address the discriminatory lack of access of rural children to optimal diabetes services, as defined by the NHMRC.

Analysis of the holistic model of paediatric diabetes care has clearly shown benefits to the patients and their families and has achieved improved glycaemic control in comparison to the pre clinic years. The HbA1c median 8.1% and mean of 8.5% of clinic patients has now improved to a point where it again compares favourably with the largest tertiary diabetes clinics in Victoria and the Hvidoere mean Hba1c of 8.2%. We intend to further improve this over the next 12 months with the increased usage of CGMS (8), expansion of the insulin pump therapy program and use of advanced communication techniques for insulin adjustment and patient support.

The model has supported the introduction of insulin pump therapy, which in itself has been shown to improve glycaemic control and produce improved quality of life (6). But IPT could not have been successfully established exclusive of the team model. The rate of IPT is almost double the IPT rate of some tertiary diabetes units in Australia. The successful initiation of IPT to a number of challenging patients has been the result of the holistic team approach.

The model was supported by a sponsored grant to allow it to be cost effective. It would become cost effective in its own right if CMBS item numbers matched the NHMRC recommendations of a multidisciplinary team reviewing the child 4 times per year (16 allied health contacts per year). Currently the CMBS will only part rebate 5 visits (total) to the CDE or counsellor under an EPC. In addition, qualified mental health nurses are not entitled to CMBS rebates under the Focused Psychological Strategies despite their skills, the paucity of workers with psychological skills in rural areas and despite the NHMRC recommendations stating that psychological interventions have been shown to improve HbA1c and psychosocial outcomes.(1) In addition, for Insulin Pump Therapy to become financially viable in a rural

community setting there would need to be another 8 rebatable items for visits to a CDE with insulin pump accreditation.

An important part of the model was to encourage patients to engage in self care and improve their awareness of diabetes and its complications. The model supports cohesive family function where possible and has developed a more personalised and realistic approach to diabetes care with the same professional people consulting with the child and family on each occasion. The multidisciplinary team approach has allowed a more positive attitude and expression of personality, which has facilitated change in the consultation behaviour by the paediatrician. No longer is the paediatrician carrying all the burden of management, which has included frequently conveying bad news or “discipline” for the non-compliant child but the holistic model has facilitated an attitude which conveys hope, positive expectation and realistic target setting.

The previously described reduced Quality of Life for rural diabetic youth has been hypothesised to be related to a sense of isolation and separateness. It is possible that the holistic clinic concept, with attention to psychosocial support is redressing the situation for those rural children given the strong survey response to feeling more supported. We believe attention to the holistic nature of diabetes management, particularly emotional and family support has reversed the disadvantages experienced by rural youth living with diabetes.

One future challenge is to address the needs and improve the care of the non-clinic patients and post adolescent patients. We firmly believe that supporting all these patients through to early adulthood is an imperative role of rural diabetes services and have extended age of management to 23 years.

Patient satisfaction is an integral part of caring for children with diabetes that has been shown to underpin adherence to treatment regimes, though in one metropolitan study (9) was not associated with improved clinical outcome. This may not be true for rural children with diabetes, as our patients showed improved glycaemic control with a parallel improvement in patient satisfaction.

The core team members recognised the emotionally demanding, vicarious traumatising nature of the work. Regular practice review was established to prevent burn out and maintain an organised enthusiastic attitude. The regular case meetings allowed us to gain a clearer picture of the major influences on families and individuals and therefore deliver a holistic, individualised care and intensive diabetes management. With consolidation of the clinic concept, expansion of our insulin pump program and expansion of Continuous Glucose Monitoring System, we are confident of further improvements in patient care and patient satisfaction.

## Conclusion

Multidisciplinary holistic child and adolescent diabetes care can be successfully achieved in a rural setting with results comparable to large metropolitan units with excellent patient and professional satisfaction. The model allows correction of the current disadvantages experienced by children and adolescents in rural areas by improving their health and emotional wellbeing and hence their quality of life. The improvements in glycaemic control significantly reduces their risks of longer term complications and hence the cost of the burden of disease on the patient, their family and the community and should be supported by more appropriate CMBS items.

## Recommendations

- Tertiary diabetes clinics should promote the holistic rural model to assist in promoting better glycaemic control, improved patient satisfaction and better quality of life for rural children with diabetes and their family.
- Allied health EPC rebatable visits for Type 1 diabetes should be increased to 16 visits per year, in keeping with NHMRC recommendations
- Credentialed Mental Health Nurses should be eligible to receive CMBS rebates for focused psychological strategies under Better Mental Health Outcomes, particularly in rural areas.
- Paediatricians in rural areas should be able to generate EPC plans for children with diabetes in rural areas to facilitate the NHMRC recommendations without further impacting upon the family.
- Onsite HbA1C should be rebatable for rural children on parity to metropolitan child diabetes clinics
- Group consultations for patients with type 1 diabetes should be equally eligible for rebate as for patients with Type 2 diabetes, who have lower complication risk.

## Acknowledgment

The establishment of the model was assisted by a Novo Nordisk Regional Diabetes Grant.

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## Presenter

**Peter Goss** has been in consultant paediatric practice in Gippsland for almost 20 years. He has been a passionate advocate for quality rural child health services and an innovator of models of care that best serve the public interest. He established the first neonatal service in the region and pioneered consultant paediatric services, including outreach service in the region. His interest in improving his regional child diabetes services has resulted in a successful model of multidisciplinary service delivery and one of the first significant insulin pump programs in rural Australia.